

Note. This public version has been edited. Photos and videos have been removed in accordance with our informed consent agreement with parents.

Enhancing Reading Instruction for Children with Down Syndrome:
Phonics, Behavioral Phenotype, and Individualization

Christopher J. Lemons, Ph.D.
University of Pittsburgh
lemons@pitt.edu

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A little about me (for those of you I don't know)...

- Assistant Professor of Special Education at Pitt - starting my 5th year.
- Research on improving reading instruction for children who do not easily learn to read (at-risk, LD, ID, DS...) and related assessment.
- Graduate work at Vanderbilt and Texas. (Undergrad at Texas, too.)
- Special education teacher prior to grad school.
- Worked on various projects at the Center (when it was UTCRLA), Scale Up, Reading First, HEC.



Who are you?

Primary Objective

- Walk through a line of research focused on reading instruction for students with Down syndrome (DS).
- Provide a *quick* overview of initial work.
- Present in more detail a current development project.
- Leave time open for related discussion.



None of this possible
without my amazing
team!!!

And.. great parents, teachers and...
THE KIDDOS!!!



TEAMWORK!
WORKING TOGETHER GETS THE GOODS!



And, much appreciation to IES for supporting this work!

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Why DS?

1.) Higher expectations for children with ID -- mostly left out of research on what we consider 'evidence-based reading instruction'. Combined with my classroom experience. **What works for them?**

2.) Predominate idea in research and field that children with DS do NOT develop PA and are therefore unlikely to benefit from phonics-based approaches. **If there is a group for whom phonics won't work, is it this group?**

3.) Group shares a common set of characteristics (behavioral phenotype) and therefore modifying based on group characteristics may be possible. **If we can do this for children w/ DS, can we do with other groups?**

Question 1) What do we know about PA and PA interventions for students with DS?

Lemons, C.J. & Fuchs, D. (2010). Phonological awareness of children with Down syndrome: Its role in learning to read and the effectiveness of related interventions. *Research in Developmental Disabilities*, 31, 316-330.



- Systematic literature review focused on PA and related interventions. (20 included studies)
- Findings:
 - **Individuals with DS < TD peers** (matched on reading-ability, mental age, cognitive characteristics, or chronological age) on PA tasks. Some differences were explained by variation in cognitive ability.
 - Significant **concurrent** and **predictive relationships** were found **between PA** and various **reading** skills for individuals with DS. Controlling for cognitive ability and/or chronological age reduced magnitude and significance in some studies.

- **Differences** in PA/reading correlations between TD and DS groups (e.g., letter sound knowledge and PA correlated for TD, not for DS). **Inconsistent** across studies. Chronological age and reading experience not controlled for.
- Four intervention studies. **Improvements** in PA skills across studies. However, there were limitations of study **quality** (e.g., design, fidelity, measurement).
- Overall, evidence that **PA likely plays a role in learning to read** and that **PA interventions may hold promise**. Challenges with comparing “apples to oranges.”
- Currently conducting meta-analysis comparing DS to non-DS ID.



Question 2) How well
will a phonics
approach work?
What are predictors
of responsiveness?

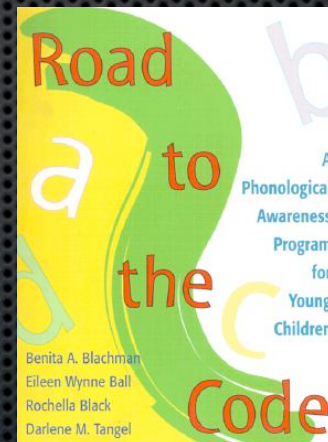
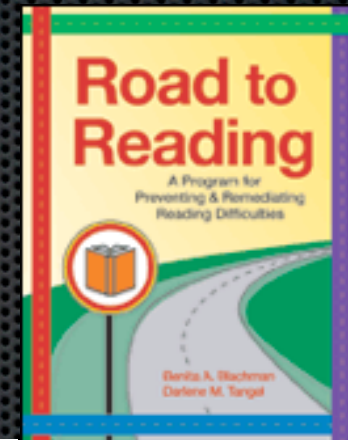
Lemons, C.J., & Fuchs, D. (2010).
Modeling response to intervention
in children with Down syndrome:
An examination of predictors of
differential growth. *Reading
Research Quarterly*, 45(2),
134-168.

- Provided **30 hours** of one-on-one instruction to 24 children with DS (7-16 yrs).
- Instruction focused on **PA, letter sounds, decoding, sight word reading, fluency**.
 - Adapted from K/1 PALS and Phonological Awareness Kit.
- Implemented with high fidelity (so, intervention is doable).
- Used individual growth modeling (HLM) to examine response and predictors of response.
- Findings:
 - Model-based (empirical Bayes) estimates of slope indicated **response for many students**:
 - 23 sight words
 - 23 letter sounds
 - 16 decodable words
 - 15 nonsense words
 - No unique predictors of sight word / letter sounds -- so, worked for most.
 - Growth in **decoding predicted by word ID** (32.4% variance); **Nonsense word by phoneme segmentation** (42.9% variance).
- Overall, good start, needs improvement for many. Supports role of PA in phonics-based reading.



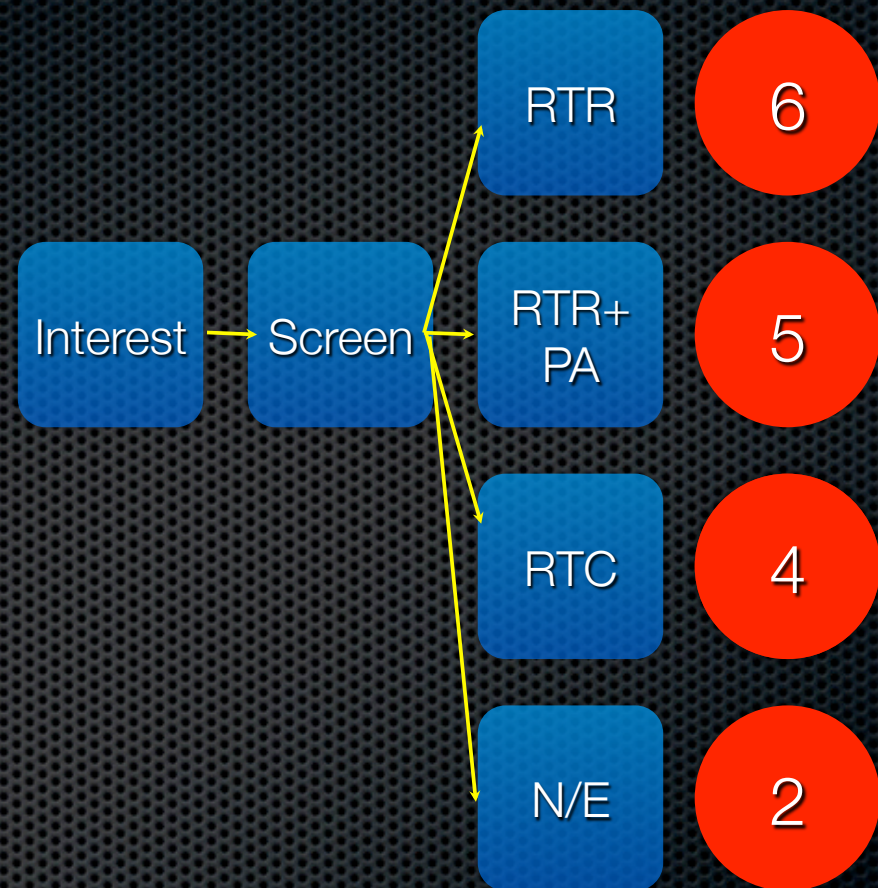
Question 3) How effective are off-the-shelf programs implemented by classroom teachers?

Lemons, C.J., Mrachko, A.A., Kostewicz, D.E., Pattera, M.F. (2012). Effectiveness of decoding and phonological awareness interventions for children with Down syndrome. *Exceptional Children*, 79(1), 67-90.



Methods

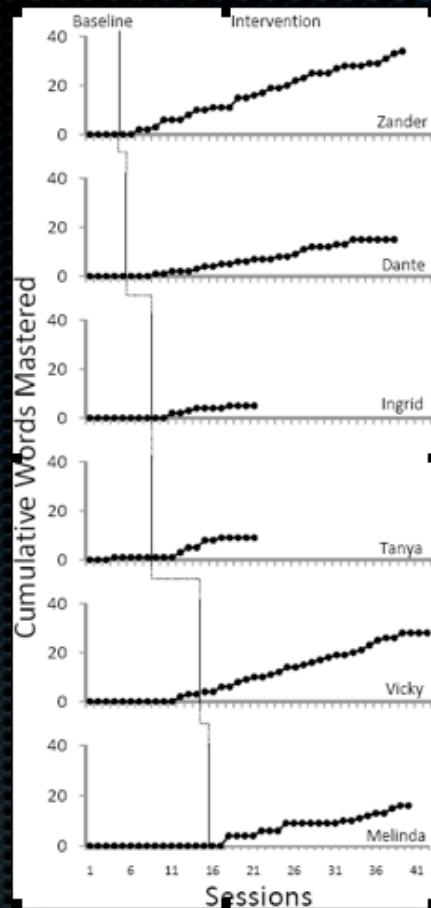
- Three multiple-baseline across participant studies.
- 15 children (ages 5-13 years)
 - All DS, ID, K-7
- 11 school staff
 - 8 SPED, 2 Rdg spec., 1 para
- Recruited through DS Center @ UPMC.
- Screened at school.
- If eligible, placed into most appropriate intervention.
- Teachers trained @ Pitt during 1 day training.
- Support, follow up provided throughout.



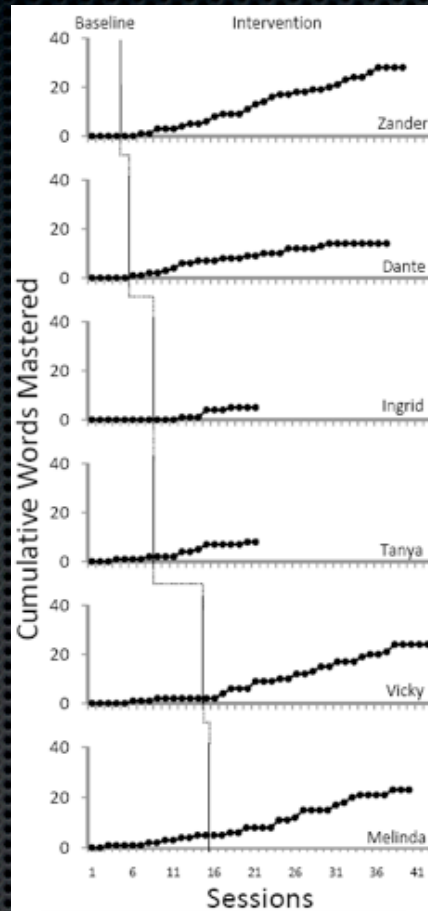
Children not eligible if couldn't repeat 3 sounds and 'clap' 3 patterns (1-1 correspondence). Placed into intervention based on knowledge of targeted sounds/words. No children were 'too high'.

Results

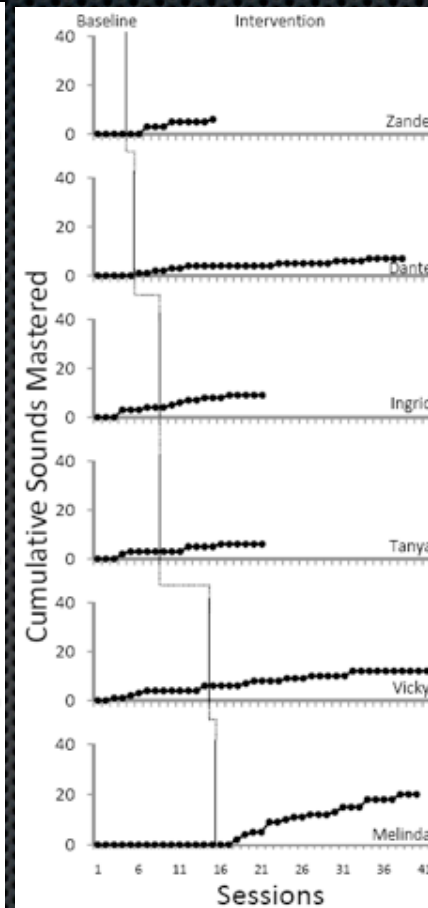
Road to Reading



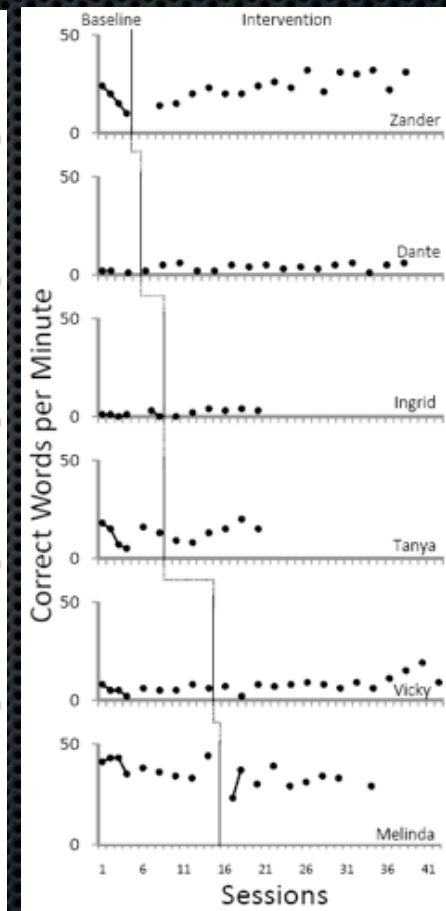
Decodable



Sight Word



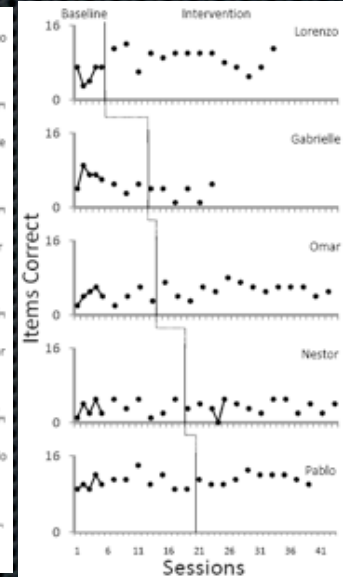
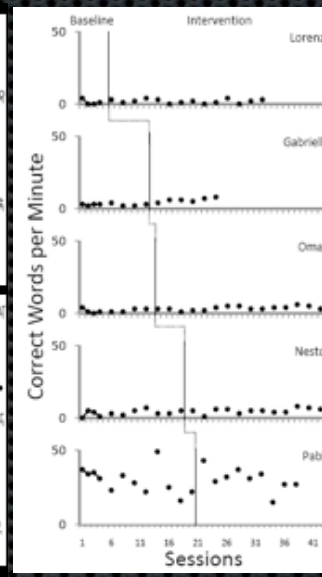
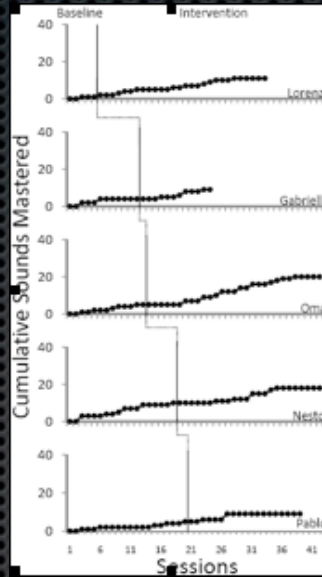
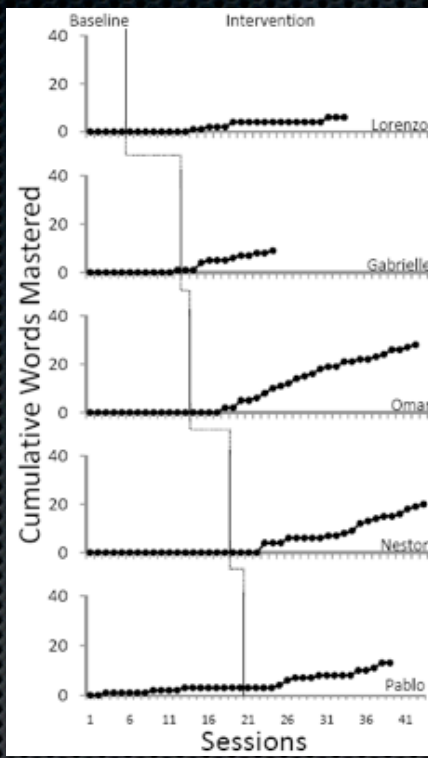
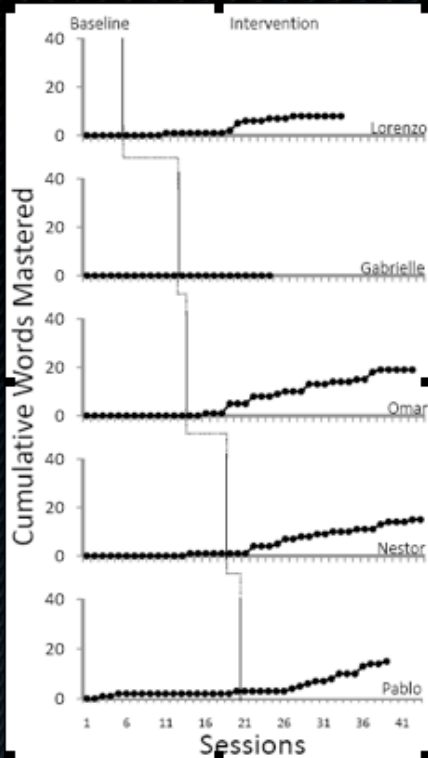
Letter Sounds



ORF



Road to Reading + PA



Decodable



Sight Word



Letter
Sounds



ORF

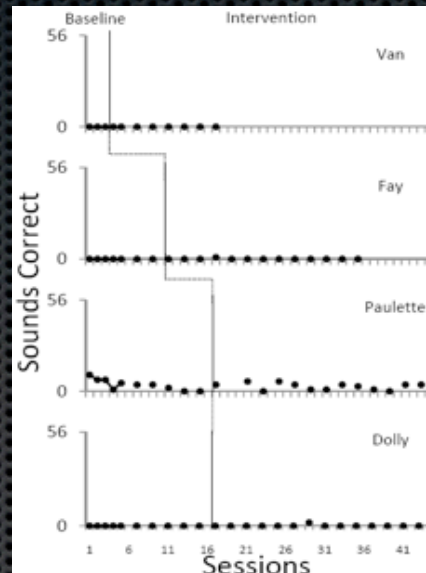
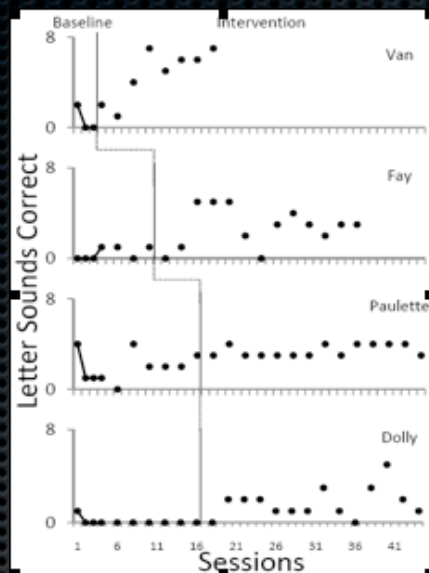


Initial Sounds

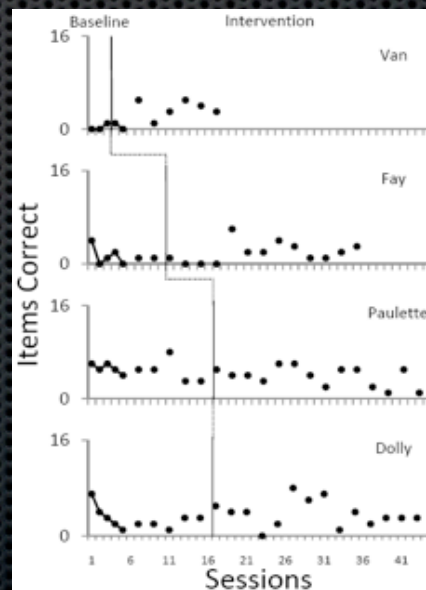
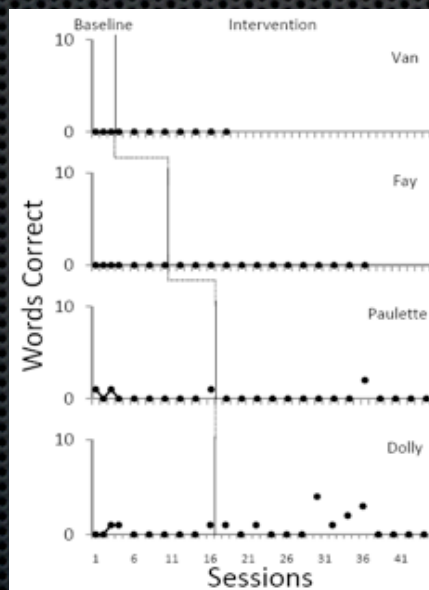


Road to the Code

Letter Sounds



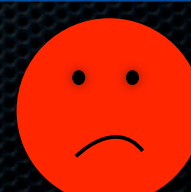
Segmenting



Blending



Initial Sounds



Teacher Feedback

1=St. Disagree; 6=St. Agree

		Mean
1)	The targeted skills are important for my student.	6
2)	The intervention was effective at teaching targeted skills to my student.	6
3)	The progress made by my student when she or he received the intervention was meaningful.	6
4)	My student benefited academically from the intervention.	5.75
5)	I feel that this intervention can be implemented by a typical teacher like me in a classroom like mine.	5.5
6)	The intervention strategies were acceptable to me.	6
7)	I could implement this intervention with currently available resources (e.g., staff, materials).	5.75
8)	I think the intervention is an effective intervention for students like my student.	5.5
9)	I will continue using this intervention in my class.	4.75

Parent Feedback

1)	The targeted skills are important for my child.	5.69
2)	The intervention was effective at teaching targeted skills to my child.	5.25
3)	The progress made by my child when she or he received the intervention was meaningful.	5.58
4)	My child benefited academically from the intervention.	5.30
5)	I would like my child's teacher to continue working on reading instruction with my child.	6.00
6)	I would like my child's teacher to continue using the intervention used in this study with my child.	5.73
7)	I think the intervention is an effective intervention for children like my child.	5.91

Maintenance **LS=SSC**

Descriptive Statistics

	N	Range	Minimum	Maximum	Mean	Std. Deviation
RTR LS	6	33.33	66.67	100.00	88.8883	13.60773
RTR HFW	6	42.86	57.14	100.00	87.4083	17.71900
RTR PRW	6	33.33	66.67	100.00	86.4217	15.25386
RTR+PA LS	5	30.00	70.00	100.00	83.5820	10.71899
RTR+PA HFW	5	100.00	.00	100.00	60.9540	36.79359
RTR+PA PRW	4	75.00	25.00	100.00	61.2500	30.65262
Valid N (listwise)	4					

For cumulative measures, what % of words checked on last maintenance trial were correct?

Discussion

- RTR components result in gains in decodable and sight word reading.
- Some gains in SSC, but not different than typical instruction.
- Little to no generalization to ORF (or nontought words).
- RTC not associated with gains.
 - Enough time? Correct measures?
- Maintenance not great - even with 'cycling' back into instruction.

So... phonics-based instruction is feasible, results in gains in directly taught skills. PA-interventions need more intensity. Teachers and parents reported favorably.

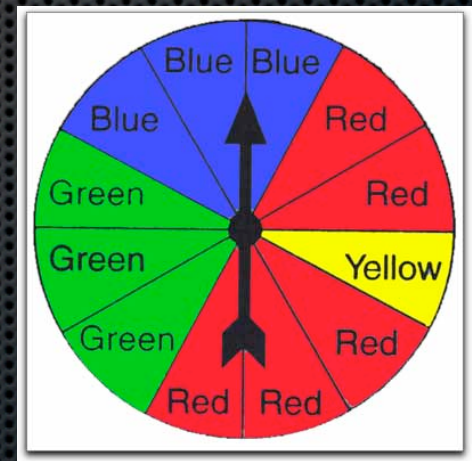
Current project

- Project ERIC: Enhancing Reading Instruction for Children with DS: A Behavioral Phenotypic Approach - Lemons, Puranik, Al Otaiba, and Fidler
- Can we get better results if we make modifications based upon the behavioral phenotype?
- I'm going to:
 - Define behavioral phenotype and overview intervention structure
 - Show a few example videos
 - Discuss assessment strategy
 - Present some data
 - Review findings
 - Discuss plans for this year.



A behavioral phenotype

- is a behavior or set of behaviors presumed to be genetically determined—the behavioral equivalent of a physical phenotype, a set of physical characteristics produced by genetic abnormality (Levitas, Dykens, Finucane, & Kates, 2007).
- In other words, a behavioral phenotype can be thought of as **an observed set of characteristics shared by a majority of people with a common genetically caused syndrome.**
- Probabilistic--higher likelihood, not certain.



For DS, includes:

Cognition and short-term memory (**relative strengths in visual processing; deficits in auditory working memory**);

Language and speech (**deficits in articulation and development of morphological/syntactic development. Receptive vocabulary strengths.**)

Social-emotional and personality-motivation. (**Strong social competence. Use of ‘positive social’ to escape tasks. Decreased ability to pursue challenging/new tasks.**)

See work of Deb Fidler or Robin Chapman for more information.

Possible modifications



- (a) capitalizing on **visual modality strengths**;
- (b) increasing the **density** and **duration** of exposure to new **vocabulary** words;
- (c) **contextualizing** language instruction;
- (d) providing alternative modes of communication to **by-pass expressive deficits**; and
- (e) supporting the development of instrumental problem solving through **chaining of behaviors** to meet goals.
- (f) increasing **ratio** of known (**easy**) material to unknown (new, challenging) material.

Overall approach.



- 10 students (5-12 years).
- 20-40/min day; 4x/week; 16 weeks.
- Craft a **new sequence of lessons that would be based around a set of core decodable words**. Highly imageable, high interest.
- Use **pictures** plus letters for subsequent activities (PA, decoding, writing).
- **Revise scope/sequence** to move harder to pronounce sounds to later (e.g., /r/).
- Target PA (first sound, blend/seg), letter sounds, decoding, reading of decodable/sight words, writing, sentence/story reading.
- Individualize behavior plans.

Lesson Components

- **Supported PA** (initial sounds; blending/segmenting).
- Core **decodable words** (learn picture; sound it out/read it fast; read in sentences).
- **Letter sounds/word building**.
- **Sight word** instruction.
- **Repeated reading**.
- **Writing** (of decodable words)
- Practice games.



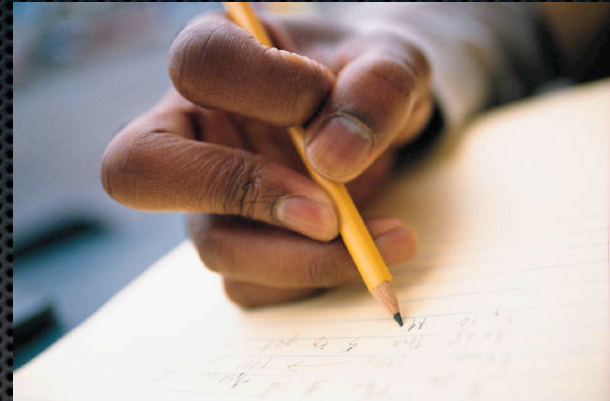
Sat! This is Sam.
Sam sat on a mat.

is

Is this Sam?
Yes it is!

This is a mat.
More mats! 4 mats.
4 more mats!
This is Sam.
Sam is on a mat.
Sam sat on a mat.

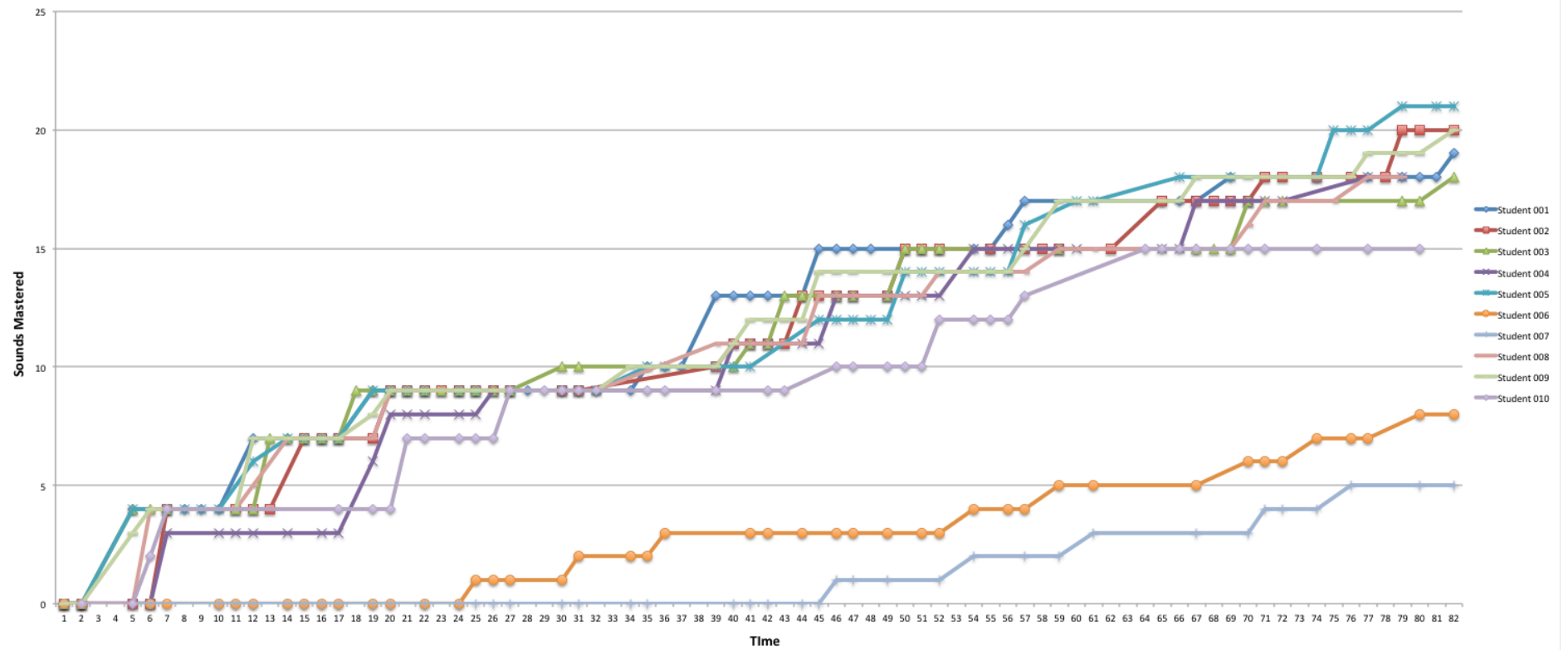
Assessment



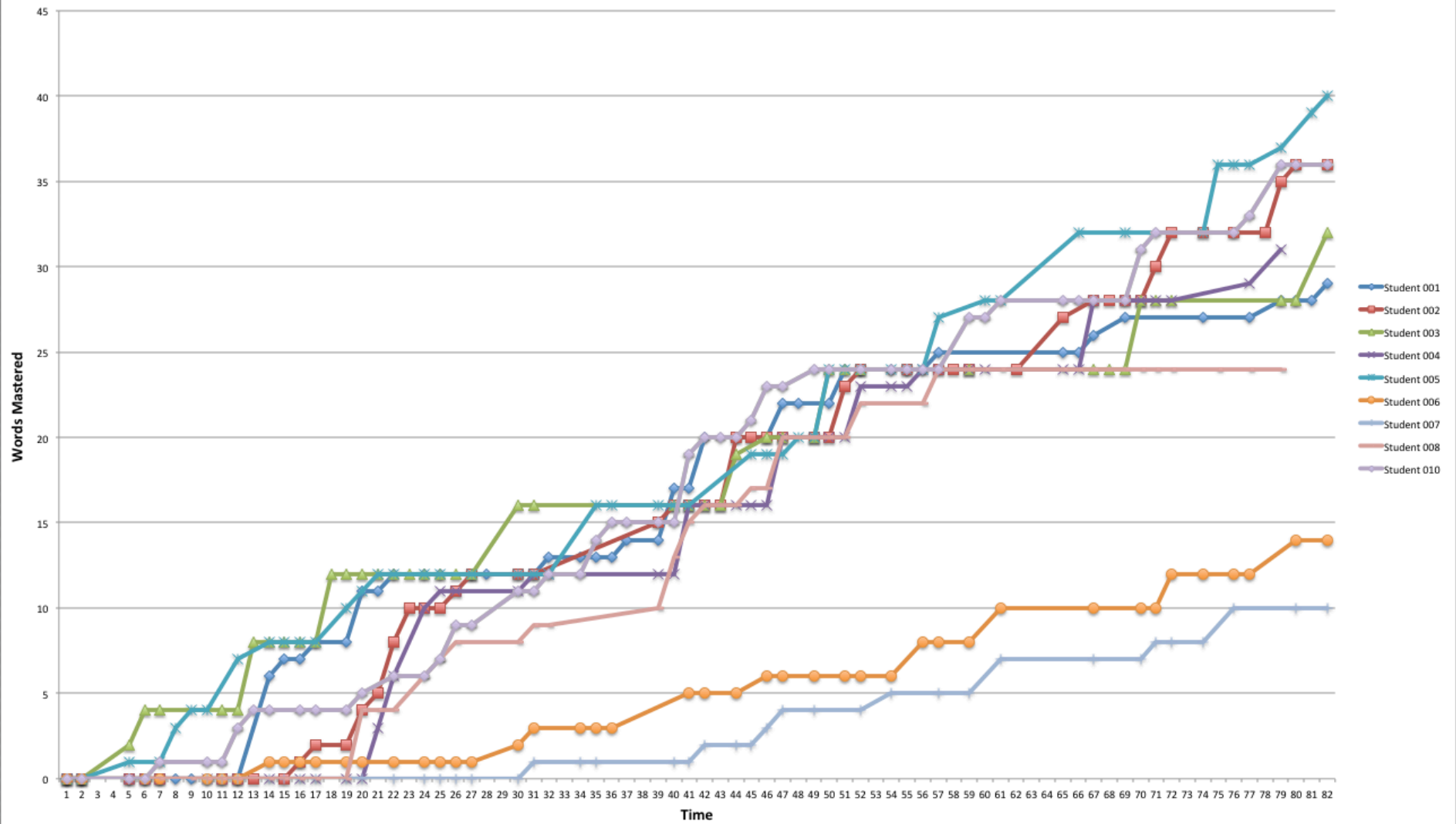
- Five 'key skills'
 - Letter sounds, initial sounds, reading of decodable words, reading of sight words, oral reading fluency.
- For each, kept track of
 - daily 'mastery measurement'
 - Did student get correct 3 days in a row during instruction
 - Weekly intervention-aligned CBM
 - Researcher-created CBM (timed, sampled our content).
 - Weekly 'full' CBM
 - Published measures (except non-taught decodable words)
- Idea was to capture proximal to distal academic gains.

Mastery Measurement Graphs

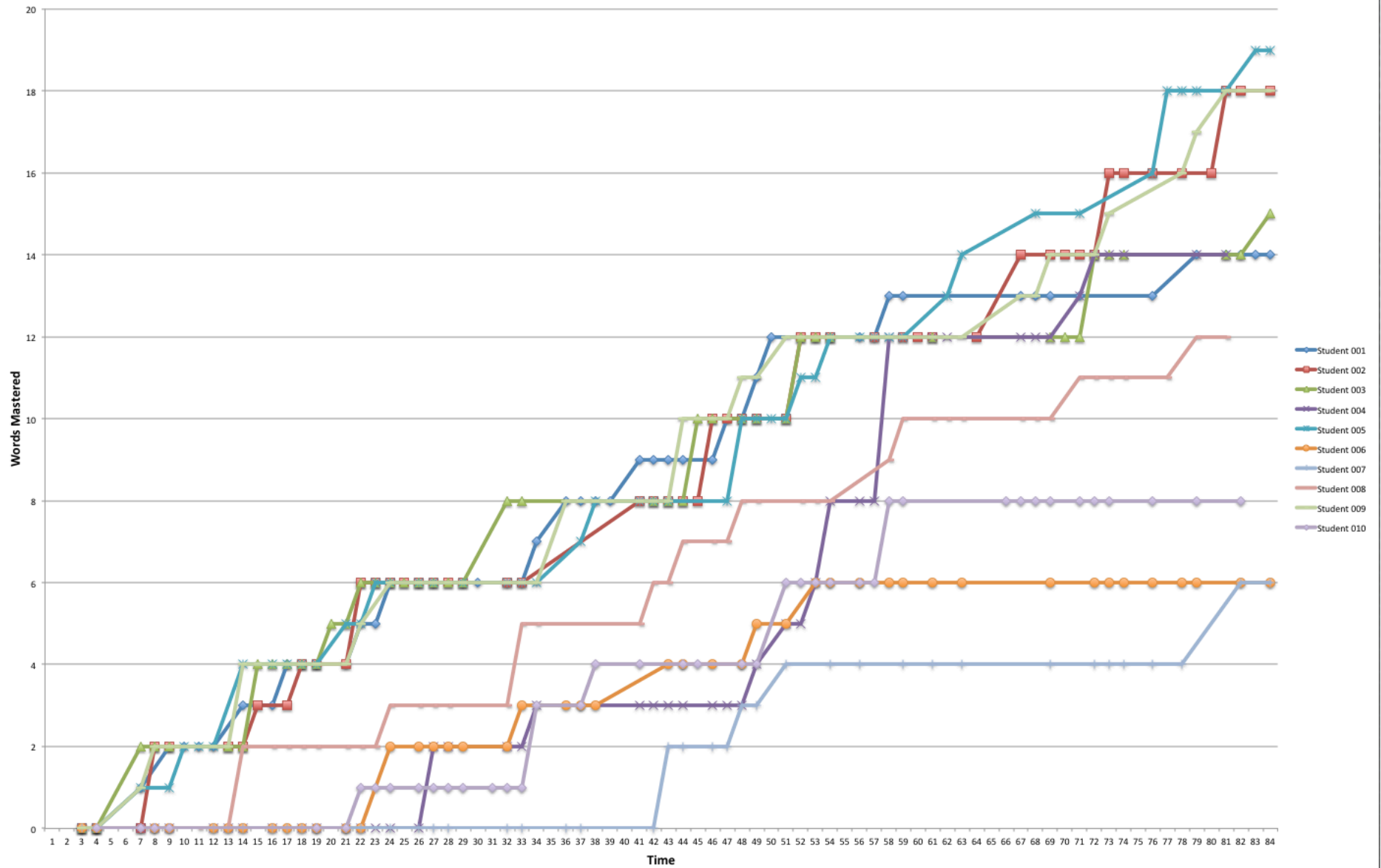
Mastery Measurement: Letter Sounds



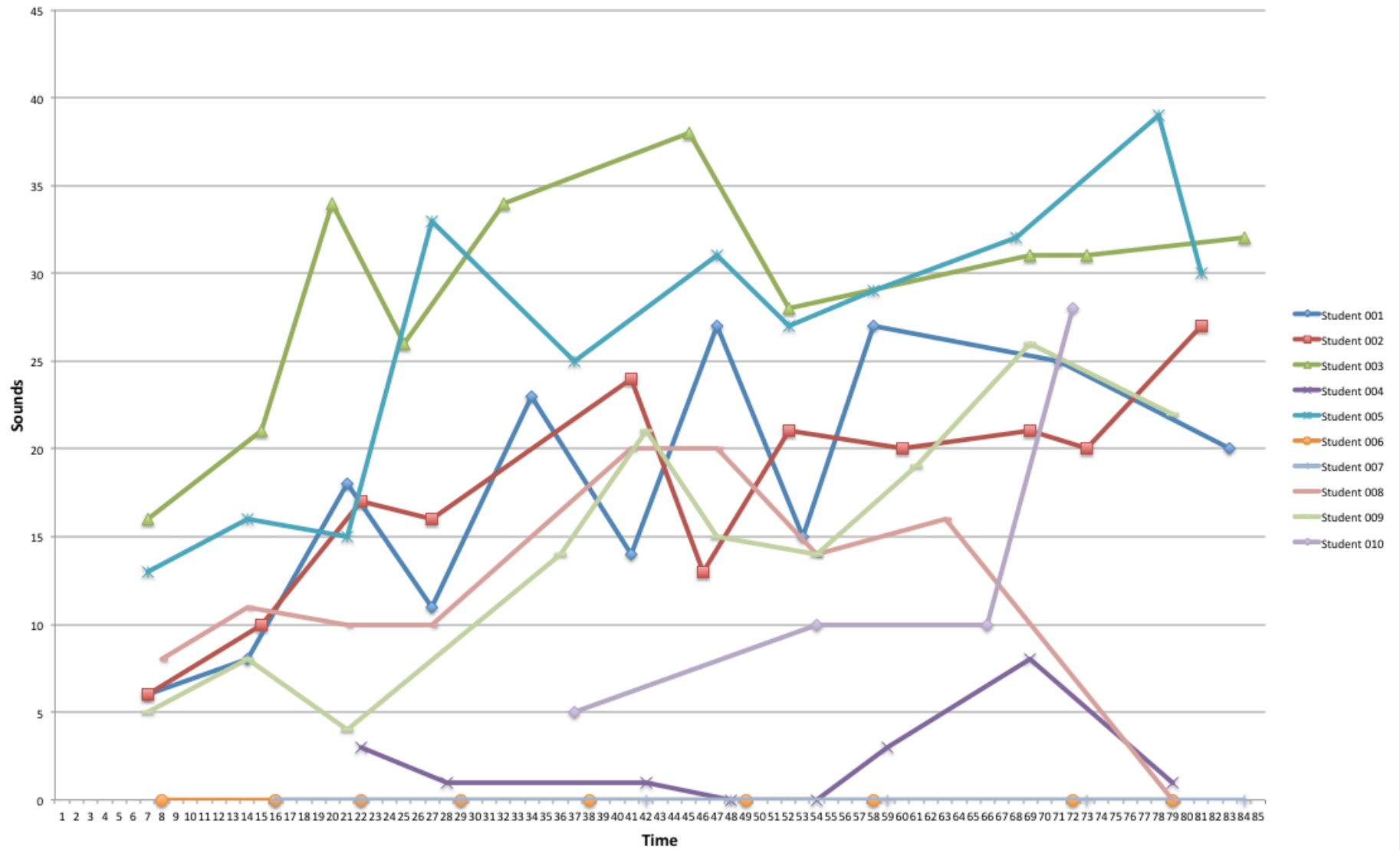
Mastery Measurement: Decodable Words

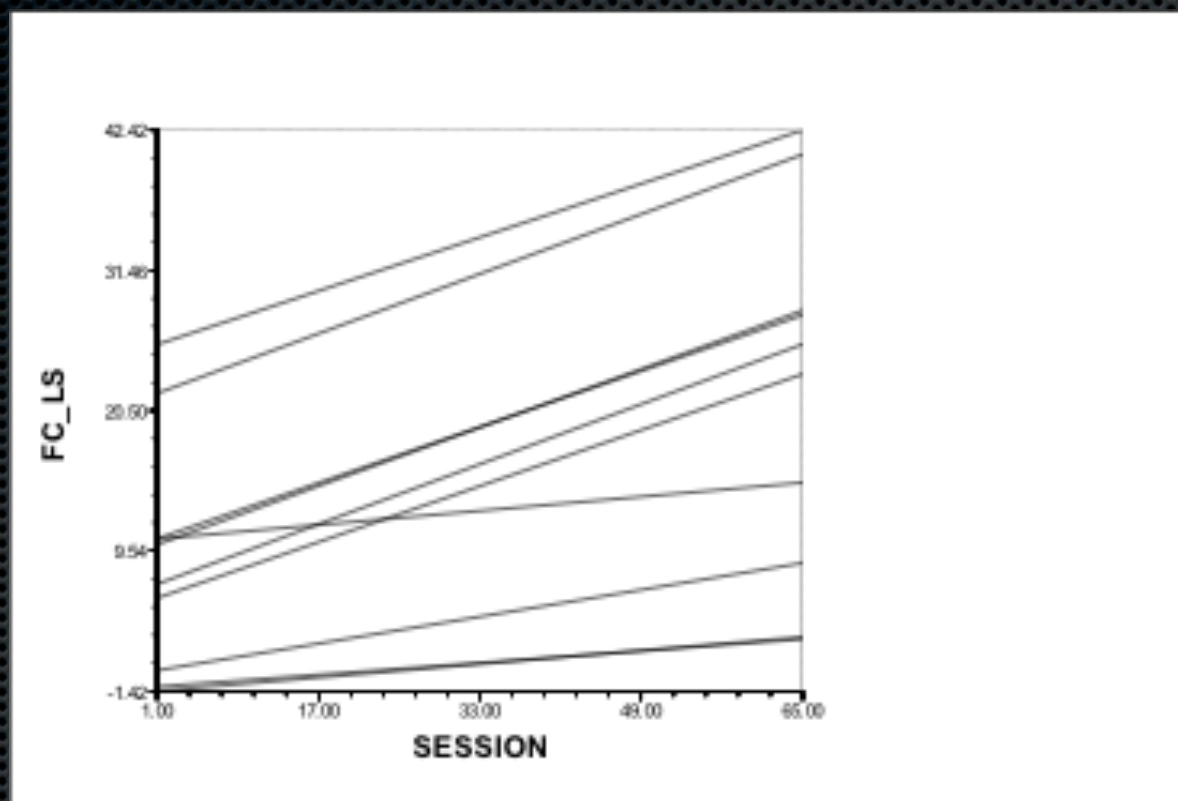


Mastery Measurement: High Frequency Words

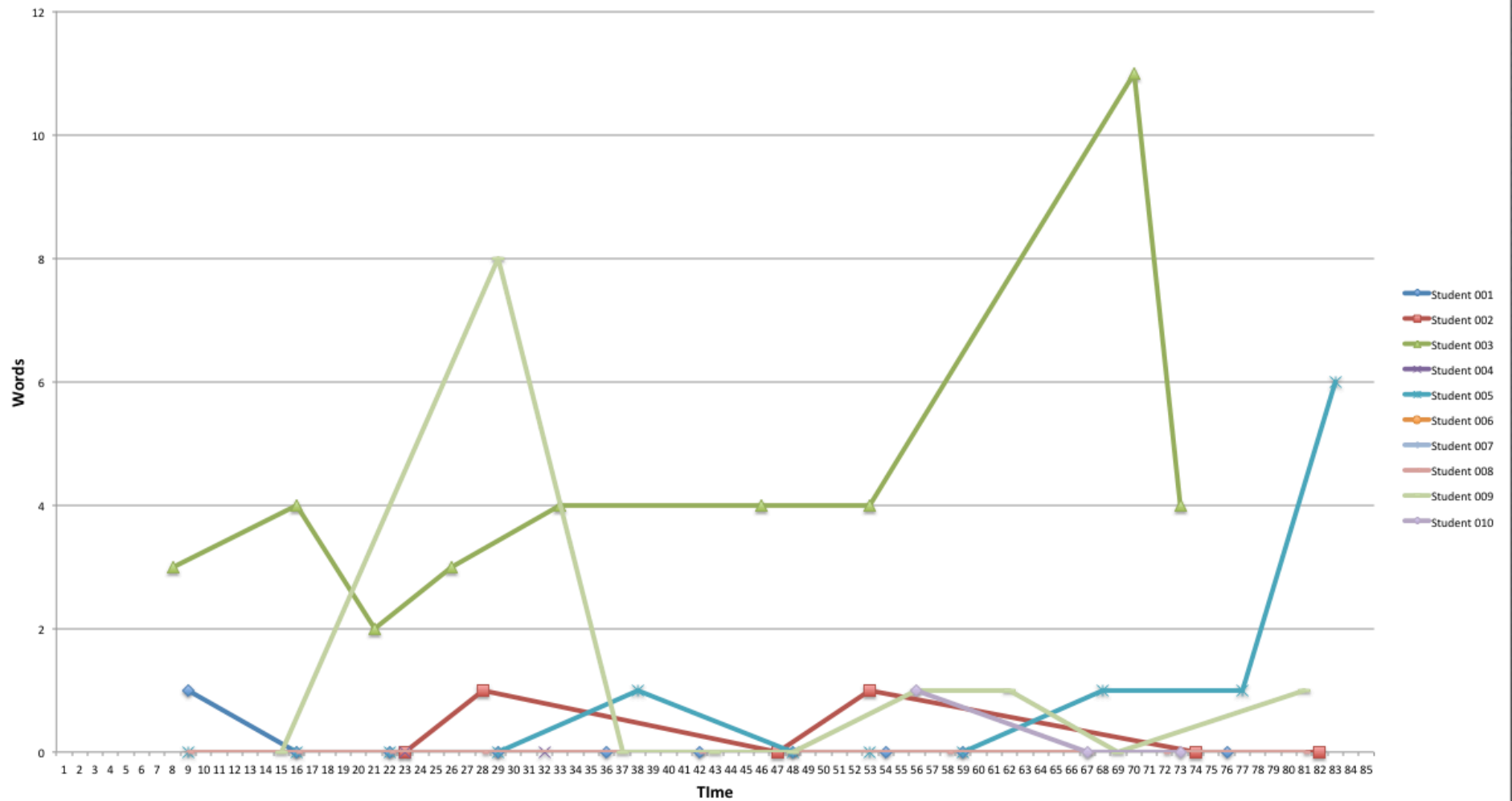


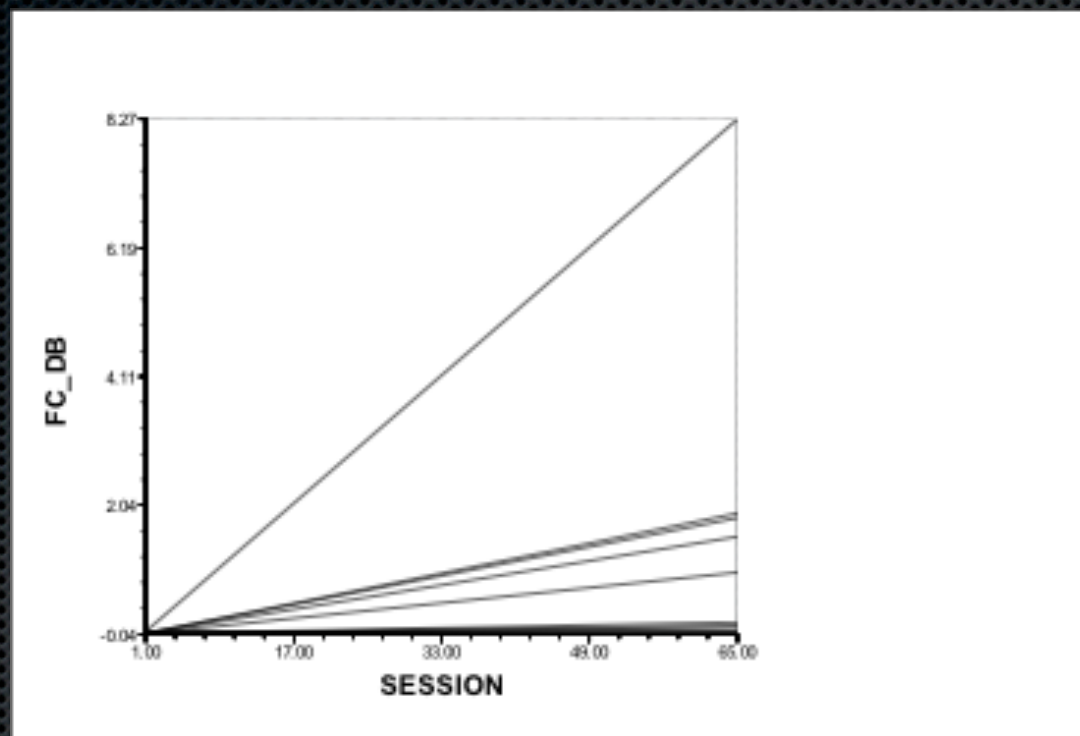
Letter Sounds: Full CBM



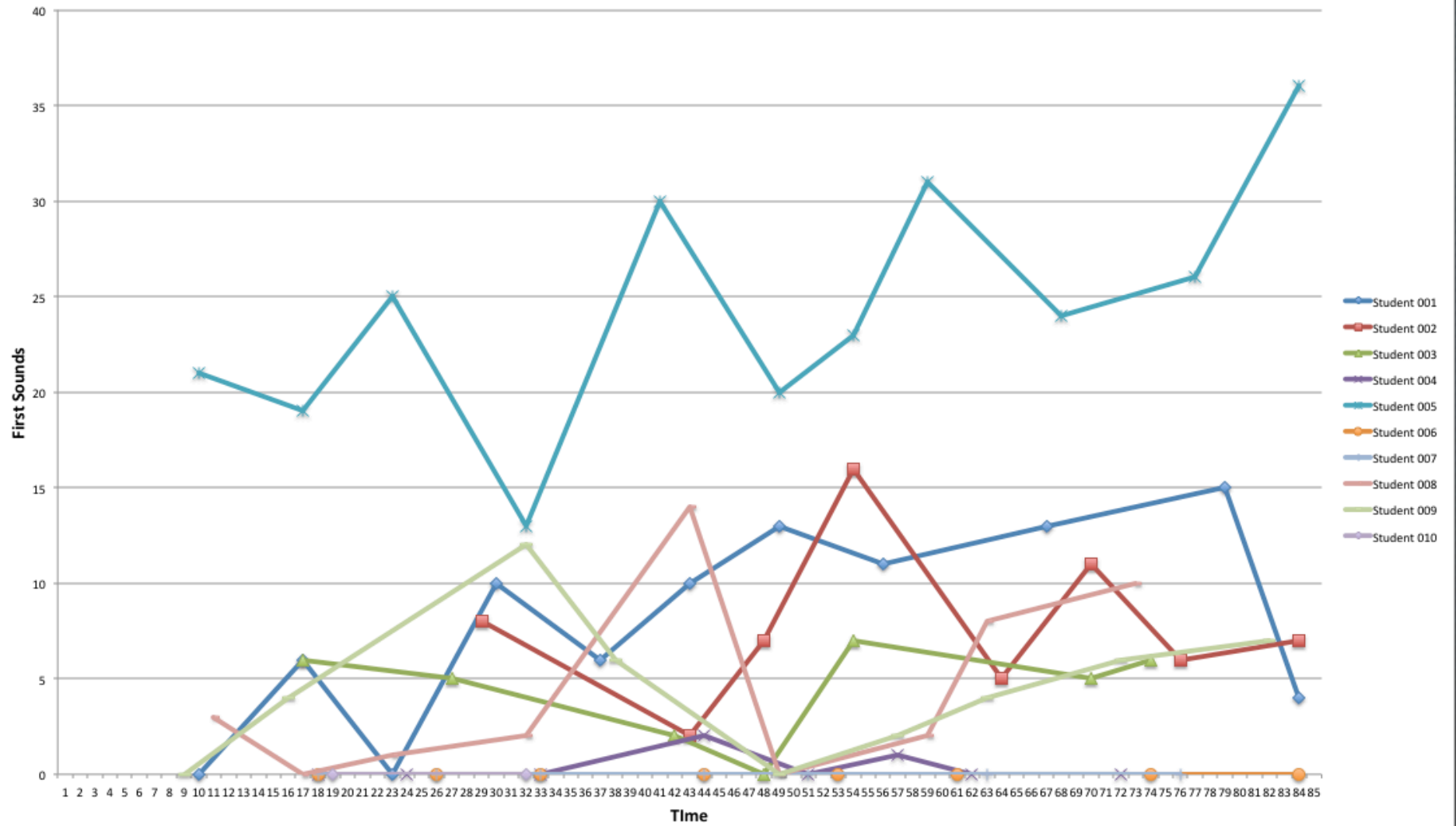


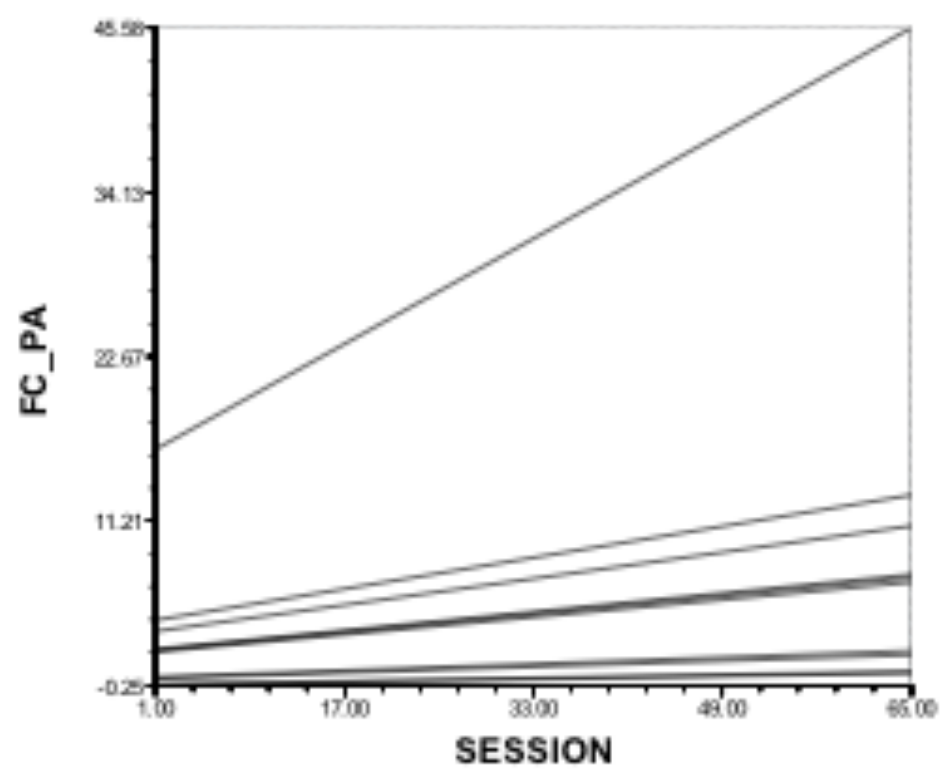
Nontaught Decodable Words A&C: Full CBM



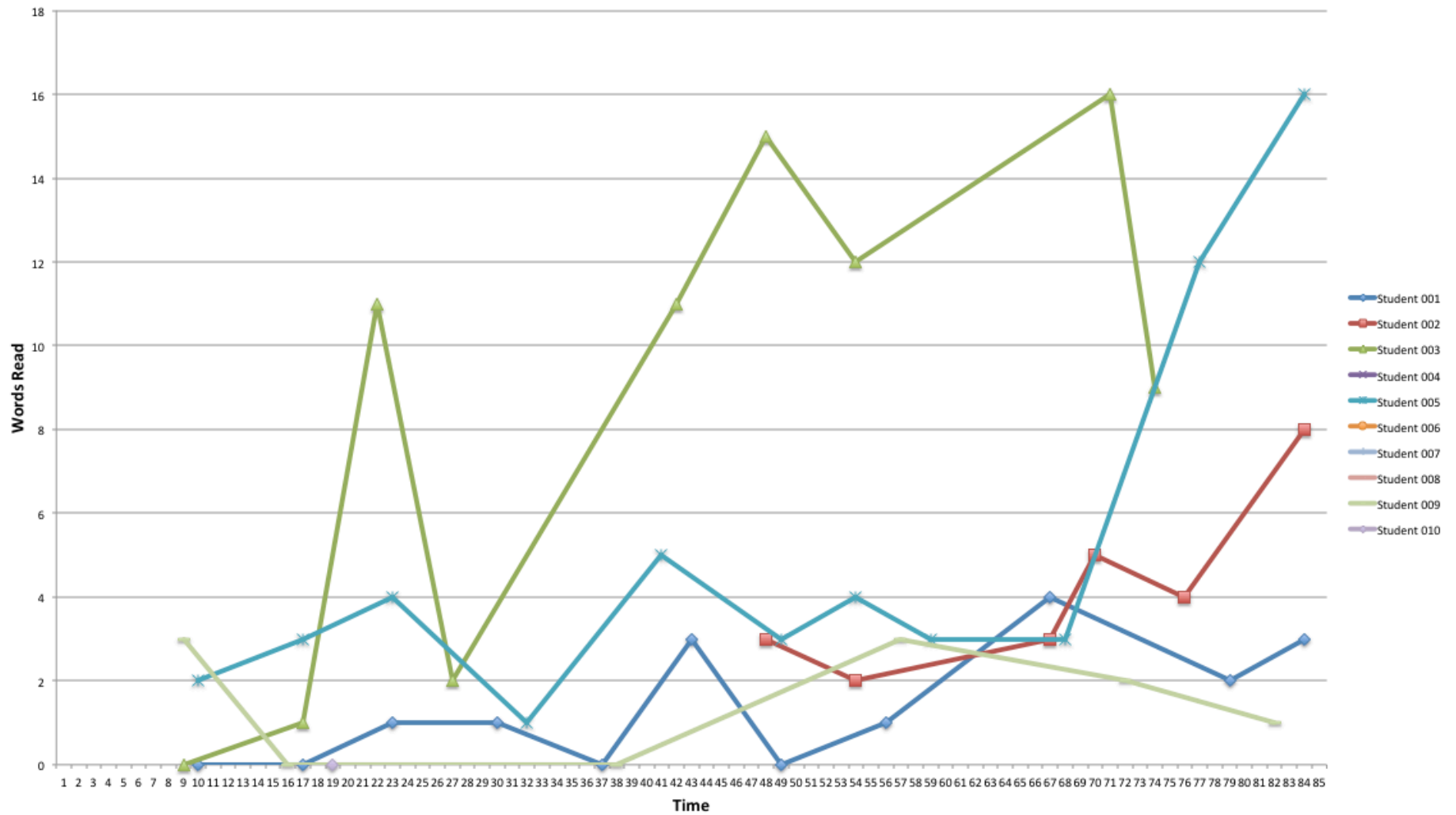


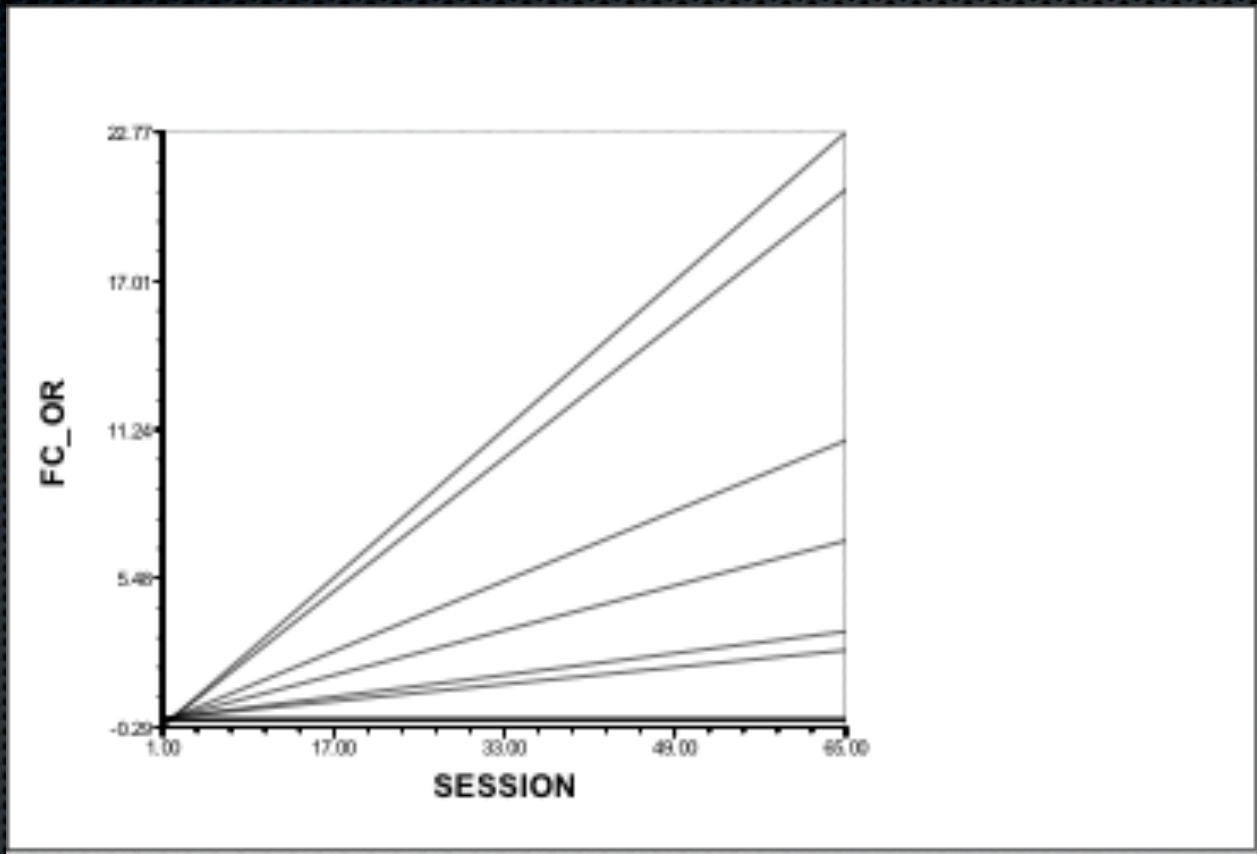
DIBELS: Full CBM





Oral Reading Fluency: Full CBM





Some
thoughts...



- Intervention was generally a success for most students.
- Students improved in directly taught skills.
- Challenges with timed measures (and correspondence with what was mastered on MM).
 - Not saying CBM doesn't hold promise for this population. Recent work (in upcoming EC) documents usefulness for 7,000+ students taking the AA-AAS.
- Fewer generalizations to non-taught skills (novel decodable words) and to higher level skills (oral reading fluency).
- Many students needed substantial individualization (particularly two students at an earlier developmental level in reading).
- Some improvements from our previous work-- especially in area of phonological awareness.





So, what's next...

- Backing up a little.
 - We don't need to recreate the wheel.
 - Going to apply 'modification kits' to RTC and RTR.
 - Evaluate in 2 MB across students SCD studies.
 - Compare 'box' to 'modified'
 - Decrease assessment, but target CBM completion
 - 'Starter set' w/ easier items
 - More direct practice.
 - But is this enough???

- Likely not.
 - These students need **intensive, individualized intervention** -- Not a 'box' or a 'manual'.
- We are also going to run a small number of students through data-based individualization (Deno & Mirkin, 1977; Data-based program modification.)
 - Going back to '**clinical**' or '**experimental**' teaching (*Smart RTI*; Fuchs, Fuchs, & Compton, 2011)
 - Use programs as an instructional platform, but modify based on phenotype, student instructional and behavioral needs, collected data and progress towards goals.
 - In other words, high quality special education.



- Aim to demonstrate that DBI is possible, that it increases learning, but-- importantly--that it is **hard to do** and that substantial support/training are needed.
- Isn't this what we should be doing for all tier 3 students?
 - Very likely **YES**.
 - For these students, we need a **PROCESS** more than a **PRODUCT**.
 - And this process will need to be more **comprehensive** (e.g., involve behavior) and (particularly for older students) aimed at **preparing students for post-secondary life** of independence, productivity, and happiness.
- Next steps for project
 - Year 3 - Teacher implementation in SCD
 - Move to efficacy trial.
 - Likely involve students with DS and ID

Questions and Discussion

Thank you!!

lemons@pitt.edu